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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[Docket No. CDC-2019-0022; NIOSH-326]

National Firefighter Registry; Request for Information

AGENCY: Centers for Disease Control and Prevention, HHS.

ACTION: Request for information.

SUMMARY: The Centers for Disease Control and Prevention (CDC) in the Department of Health and Human Services (HHS) announces the opening of a docket to obtain information regarding the development and maintenance of a voluntary registry of U.S. firefighters. The purpose of the Registry will be to collect health and occupational information for the purpose of determining cancer incidence. CDC is seeking input on approaches to maximizing firefighter participation in the Registry and coordination of data collection.

DATES: Comments must be received by [INSERT DATE 60 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER].

ADDRESSES: Comments may be submitted electronically, through the Federal

eRulemaking Portal: <http://www.regulations.gov>, or by sending a hard copy to the NIOSH Docket Office, Robert A. Taft Laboratories, MS-C34, 1090 Tusculum Avenue, Cincinnati, OH 45226. All written submissions received must include the agency name (Centers for Disease Control and Prevention, HHS) and docket number (CDC-2019-0022; NIOSH-326) for this action. All relevant comments, including any personal information provided, will be posted without change to <http://www.regulations.gov>.

FOR FURTHER INFORMATION CONTACT: Rachel Weiss, Program Analyst, 1090 Tusculum Avenue, MS: C-48, Cincinnati, OH 45226; telephone (855) 818-1629 (this is a toll-free number); email *NIOSHregs@cdc.gov*.

SUPPLEMENTARY INFORMATION: The Firefighter Cancer Registry Act of 2018 (42 U.S.C. 280e-5) requires that CDC develop and maintain a voluntary registry of firefighters (Registry) to improve the nationwide monitoring of cancer rates among firefighters and to make the resulting epidemiological information and analysis publicly available. In order to develop the Registry, CDC is soliciting public comments from any interested party on a strategy for inclusion of firefighters in the Registry and to coordinate data collection activities.

The National Firefighter Registry will be constructed primarily for the purpose of determining cancer incidence and trends among firefighters. Data submission will be voluntary. In order to develop an accurate picture of cancer incidence among the firefighting community, the Registry will be designed to collect information on volunteer, paid-on-call, and career firefighters, independent of cancer status or diagnosis. Such

information may include basic demographic information, number of years and time period(s) as an active firefighter, number of fire incidents attended, details of any cancer diagnosis, additional risk factors such as smoking or drug use, and relevant medical history. This information will be collected periodically from Registry participants and other sources. CDC is further required to ensure that data and analyses in the Registry are available to the public, as appropriate, subject to relevant Federal and state privacy protections such as de-identification of personally identifiable information.

CDC is considering three different strategies to recruit participants into the Registry, as described below. Each approach has strengths and limitations, and it may be necessary for CDC to use a combination of all three strategies in order to reach reliable conclusions applicable to the general population of firefighters as well as specific subgroups. Each approach proposed below will require obtaining informed consent from every firefighter who agrees to participate in the Registry, prior to the collection of data. The informed consent document would describe the purpose of the Registry; how health, occupational, and contact information will be maintained, updated, and potentially used; the privacy protections afforded by applicable Federal laws and procedures to protect such data; and other relevant information.

Recruitment strategy options

1. Convenience Sampling – Open Enrollment

CDC would develop a secure web portal to allow current and former volunteer, paid-on-call, and career firefighters to provide information to the Registry, including

demographic information, as well as relevant occupational and personal health history.

CDC would consult with fire service stakeholders on methods to raise awareness and to notify their members about the open enrollment web portal.

An open enrollment design may limit the ability of researchers to make statistical inferences because those who enroll in this manner may be different from the general population of firefighters. Nevertheless, Registry data from these participants may be helpful to CDC researchers in generating hypotheses for future research studies. Further, this approach would provide the opportunity for any fire service members to participate in the Registry and for CDC researchers to have a quick and cost-effective means for cross-sectional analysis of characteristics relevant to firefighter health and safety.

2. Organizations-Level Probability Sampling – Recruit Participants through Professional Associations

CDC would consult with firefighter organizations to identify current and former members who worked during a specified time frame (*e.g.*, 2000-2018) for the purposes of direct solicitation. These organizations represent different groups of currently employed (and, in some cases, former) firefighters, including career and volunteer firefighters; sub-specialties of the fire service, such as arson investigators, instructors, wildland firefighters, and airport rescue firefighters; and specific demographic groups, such as minority and female firefighters, and volunteer firefighters. This strategy would allow CDC to contact members from these organizations for voluntary participation in the Registry.

A strength of this approach is that, because firefighter organizations reach a vast majority of the firefighter workforce, populations representative of specific subgroups of firefighters are more likely to be represented. However, recruiting participants using this method alone may be time-intensive and costly, and could result in a limited sample that is not representative of the entire population of firefighters.

3. Fire Department-Level Probability Sampling – Study Population from Select Fire Departments

CDC would obtain a list of fire departments from the U.S. Fire Administration's National Fire Department Registry and other sources to request identification of current and former firefighters who worked during a specified time frame (*e.g.*, 2000-2018). CDC would then match the rosters of current and former firefighters against the National Death Index (NDI) to determine vital status. Living individuals would be directly contacted (or directed to the web portal) for voluntary recruitment into the Registry. For those firefighters determined to be deceased, the cause of death would be included in the Registry database.

This recruitment method would facilitate reaching large numbers of firefighters by obtaining immediate access to fire department rosters of current and former employees. Depending on the participation rate, this method could yield a Registry population representative of the general population of firefighters and inclusive of specific subgroups of firefighters. However, this approach would require CDC to obtain approval from individual fire departments and coordination with their personnel systems, in addition to contacting members directly, which may be time-intensive and costly.

CDC is seeking input from all interested stakeholders

In order to recruit firefighters to participate in the National Firefighter Registry, CDC seeks input and advice from all interested stakeholders in response to the following questions:

1. How should CDC define “firefighter” for the purpose of creating the Registry?
2. What are the strengths and weaknesses associated with CDC using a combination of all three of the recruitment and enrollment strategies described above?
3. If CDC were to focus on only one or two of the enrollment approaches described above, which one(s) should be used, and why?
4. Are there other recruitment and enrollment methods that CDC should consider? If so, please describe them.
5. What are some ways to maximize firefighter participation in the Registry?
6. Which under-represented or under-studied groups of firefighters should be included in the Registry? Are there unique data collection needs that should be considered to allow sufficient representation of minority, female, and volunteer firefighters? Are there any other unique characteristics of these under-represented or under-studied groups that should be considered or addressed in the Registry?
7. What are the preferred methods for communicating with firefighters in order to increase awareness of the Registry and to communicate research findings?

8. If CDC were to solicit participation from fire departments, what criteria should be used in selecting those departments?
9. What are some ways to maximize the participation of fire departments in efforts to recruit firefighters?
10. What are strategies that can be used to recruit volunteer fire department members?
11. What are strategies that can be used to solicit cooperation of fire departments for the purpose of recruiting women and minority firefighters?
12. Do volunteer fire departments retain employment records and fire incident records?

Dated: March 25, 2019.

Sandra Cashman,

Executive Secretary,

Centers for Disease Control and Prevention.

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